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TITLE: Evaluation of a Peer-Staffed Hotline for Families Who
Received Genetic Testing for Risk of Breast Cancer

PRINCIPAL INVESTIGATOR: James C. Coyne, Ph.D.
Pamela J. Shapiro, Ph.D.

CONTRACTING ORGANIZATION: The University of Pennsylvania
Philadelphia, Pennsylvania 19104-3246

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| 7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) The University of Pennsylvania Philadelphia, Pennsylvania 19104-3246 E-Mail: jcoyne@mail.med.upenn.edu | | | 8. PERFORMING ORGANIZATION REPORT NUMBER | |
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| 13. Abstract (Maximum 200 Words) (abstract should contain no proprietary or confidential information) This project proposed to develop, implement, and evaluate a peer-staffed toll-free hotline for individuals at high risk of developing hereditary breast cancer, either through family history or known BRCA1/2 mutations. The project is designed to demonstrate the acceptability and effectiveness of this tool for meeting the needs of these individuals and their families, and documents the range of problems for which assistance is sought. We have designed and implemented a refined peer counselor protocol that can be disseminated in larger multiple component peer-support packages. The Helpline Manual and Resource Guide was completed and distributed to our volunteers as part of an intensive training program. We successfully established the hotline, now called The Penn/F.O.R.C.E Telephone Helpline for Individuals Concerned about Hereditary Breast and Ovarian Cancer," and opened the phone lines to the public on December 2, 2003. To date caller response to this service has been enthusiastically positive and has resulted in uptake of referrals to genetic counselors and gynecologic oncologists. Our counselors have addressed both psychosocial and practical issues associated with knowledge of mutation status, anxiety about personal and familial risk, communication difficulties with family and health professionals, concerns about discrimination, and difficulties accessing appropriate medical and support services. | | | | |
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Introduction

This project involves implementation and evaluation of a toll-free hotline for women with a strong family history of breast and/or ovarian cancer, those tested for BRCA 1/2 mutations, and the families of tested individuals. The hotline addresses a pressing need for support and information among these women and their family members. The hotline is staffed by trained peers who have previously received genetic counseling regarding risk of hereditary breast and ovarian cancers. This project will serve to articulate the largely uncharted long-term needs of this rapidly growing group and is responsive to the geographic dispersion and the isolation of these families. Our clinical experience has been that families in which results of genetic testing have been disclosed are geographically dispersed and lack resources in their immediate communities. The hotline also builds on our experience with a peer counseling training and support program staffed primarily by mutation carriers, as well as grassroots efforts in Britain. We have designed and implemented a refined peer counselor protocol that can be disseminated in larger, multicomponent peer-support interventions. The Helpline Manual and Resource Guide was completed and distributed to our volunteers as part of an intensive training program. In a unique collaboration between the University of Pennsylvania and a nonprofit agency, *Facing Our Risk of Cancer Empowered*, we successfully established the hotline, now called The Penn/F.O.R.C.E Telephone Helpline for Individuals Concerned about Hereditary Breast and Ovarian Cancer,” and opened the phone lines to the public on December 2, 2003. This project was designed to demonstrate the acceptability and effectiveness of this tool for meeting the needs of these individuals and their families, and to document the range of problems for which assistance is sought. To date caller response to this service has been enthusiastically positive and has resulted in caller uptake of referrals to genetic counselors and gynecologic oncologists. Our counselors have addressed both psychosocial and practical issues associated with knowledge of mutation status, anxiety about personal and familial risk, communication difficulties with family and health professionals, concerns about discrimination, and difficulties accessing appropriate medical and support services. This is the first hotline tool of its kind with empirical support.

Body

This project received notification of final approval by the Department of Defense Grants Officer on April 1, 2003. A no-cost extension was filed and approved to allow sufficient time to implement the hotline and complete evaluations. After implementation on December 2, 2003, caller response demonstrated that there was indeed a pressing need for this service and we requested a second no-cost extension to continue the service for an additional year, if approved, the award period extends to July 15, 2005.

Overview: Following a series of consultations, we joined with Dr. Susan Friedman founder of the web based organization, *Facing Our Risk of Cancer Empowered* (F.O.R.C.E.) to plan and implement the hotline. Dr. Friedman is a hereditary breast cancer survivor and nationally known advocate for women with known BRCA1/2 mutations and their families. Her organization provides information, resource referrals, and support to women who are at high risk for developing hereditary breast cancer. Through her advocacy efforts and work as Executive Director of F.O.R.C.E., Dr. Friedman has assembled a network of high-risk women, known BRCA1/2 mutation carriers, women who have received genetic counseling, and breast cancer survivors who are familiar with the issues facing high risk women and their families and understand the importance of access to accurate unbiased information, community resources, and

peer support. We currently have 17 volunteers covering regular shifts on the Helpline. Because our counselors are geographically diverse, we are able to provide both early morning and evening call-in hours. The original Helpline schedule included several hours of weekend access; however, after an analysis of call volume and time we determined that additional weekday access would better serve the needs of callers. Current hours of operation appear in Table 1. The online description of the Helpline at The F.O.R.C.E. website may be accessed at <http://www.facingourrisk.org/upenn/helpline/details.php>

Table 1. Helpline Hours of Operation

| | |
|-----------------------------|----------------|
| noon - 2 pm (Eastern time) | Monday |
| 10 am - noon (Eastern time) | Tuesday-Friday |
| 7 pm - 9 pm (Eastern time) | Tuesday-Friday |

Training: We previously reported that Dr. Friedman, Dr. Pamela Shapiro, and a core group of volunteers attended a training conference sponsored by the New Jersey branch of the Alliance of Information and Referral Systems. This training included workshops on active listening techniques, use of self-help groups, and crisis intervention techniques. After attending the conference and receiving feedback from our core volunteers, we decided that there were a number of issues we needed to address with more detail in our volunteer training sessions and postponed the planned opening of the Helpline from late October until early December. Drs. Shapiro and Friedman worked together to develop a comprehensive training protocol including readings on genetic risk of breast and ovarian cancer, readings on active listening skills and peer-support along with strategies for meeting callers' needs, guidelines for surveillance among high risk individuals, guidelines for handling difficult and inappropriate callers, practice call scripts demonstrating variation in caller needs and peer counselor resolution, and a complete review of our comprehensive resource/referral guide (described below). These materials were organized into a training and resource binder and sent to all volunteers two weeks prior to their scheduled training with instructions to review these materials and to complete and study the assigned readings. The original *Telephone Helpline Training & Resources* (THTR) is available upon request.

Because the peer counselors are geographically diverse, training was conducted in a series of 3-hour conference calls. All materials in the THTR were thoroughly reviewed and practice call-scripts were dramatized, followed by questions, discussion, and clarification of core issues. Volunteers were encouraged to contact either Dr. Friedman or Dr. Shapiro with questions at any time. Procedures for inviting callers to participate in the Penn study and to insure caller confidentiality were explained. Additional conference calls were conducted after the Helpline opened to reinforce techniques and procedures, to share strategies for handling specific questions, and to keep the group informed of project progress. Finally, Heather Hampel, M.S., C.G.C., a member of the FORCE Health Advisory Board, conducted a training conference call discussing important issues in genetic counseling and answering volunteers' questions.

The Resource Guide: The Telephone Helpline Resource Guide is a 72 page "growing" document that is revised as new information and resources become available and as originally

listed resources change or become out of date. The guide includes both telephone and internet resources for general cancer information, genetic risk information, information pertaining to insurance and privacy issues, guides for finding psychosocial and healthcare support, as well as directories of regional health care professionals specializing in HBOC. Our counselors are trained to provide appropriate referrals to meet callers' informational and support needs.

Public Awareness: A press release from the University of Pennsylvania was issued a week prior to opening the Helpline. The announcement was disseminated through Reuters Health and was widely available on Internet health sites. Additional coverage of the Helpline was provided by television and radio news spots highlighting genetic issues in cancer, and by items in *Redbook* and *Prevention* magazines. Bookmarks and flyers advertising the Helpline were distributed by volunteers at the University of Pennsylvania and associated facilities, at breast cancer conferences and health fairs, and at health centers across the country.

The PennHelpline Evaluation Study: Evaluation of the helpline service began immediately after the first call. Callers who agree to participate in the Penn study provide telephone assent to be called by a member of the study staff and then complete the brief follow-up goal attainment interviews. No information is maintained on callers who do not agree to participate in the Penn study.

Key Research Accomplishments

- We have designed and implemented a refined peer counselor protocol that can be disseminated in larger, multicomponent peer-support interventions.
- We have successfully implemented the Penn-F.O.R.C.E. Helpline service and the Helpline evaluation study.
- To date we have received 233 calls from individuals wanting to speak with our counselors. Of these callers, 127 have agreed to participate in the Penn study, and 117 have completed interviews. A number of additional calls were from professionals and organizations seeking information about the Helpline services.

Reportable Outcomes

Currently, only demographic data is available for our callers. Coding and preparation for analyses of the goal attainment scale is under way.

Age: Mean age = 47 years, Range = 27-79 years

Marital Status: 76% Married, 10% Single, 11% Divorced or Separated, 3% Widowed

Ethnicity: 89% Caucasian, 4% African-American, 1% Asian, 6% Hispanic, 5% Other

Education: High School Graduate 22%, Trade School or Some College 29%, College Graduate 21%, Graduate or Professional Training 28%

Income: 24% < \$29,000, 12% \$30,000-\$49,999, 64% ≥ \$50,000

Conclusions

Both caller volume and community interest demonstrate the need for this service among women and family members at risk for HBOC. The Penn-F.O.R.C.E. Helpline has been enthusiastically received by the high risk community and calls continue to come in regularly.

References

None

Appendices

None